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The Family Medical History: Assessing Patient Understanding of Diabetes Mellitus

RACHELLE S. DOODY AND NELLIE P. GROSE

In this preliminary study, we attempted to determine whether diabetic subjects with a positive family medical history for diabetes have a better understanding of their own disease (ie., of its course, treatment, and genetic characteristics) than diabetic subjects without diabetes in their histories. We interviewed 50 diabetic subjects and scored their responses to determine their understanding of diabetes in general and in their own cases in particular. The data were analyzed using the Student's *t* test and chi-square analysis. Overall, patients with positive histories did not have significantly higher understanding than patients with negative histories. However, if patients had extensive exposure to the affected relative, or if that relative was a spouse or a parent, the patients' understanding was significantly higher ($P < 0.05$). Educational level, age, and duration of diabetes did not affect patients' understanding. The data suggest that the family medical history can be a valuable teaching model, once we redefine it so as to reconcile patient concepts about illness with physician concepts of disease. *DIABETES CARE* 4: 285-288, MARCH-APRIL 1981.

There have been few publications that define exactly what constitutes a complete family medical history, and even fewer reports on how such a history influences patients' understanding of diabetes mellitus. We believe that patients' understanding of their states of illness and health influences not only the course of their disease, but their families' quality of life as well, and that the family medical history can generate effective models for educating patients about disease. In this study, we investigated some of the variables within the family histories of 50 patients with adult-onset (type II) diabetes mellitus to see how these variables may have influenced general understanding of the disease, including its course, treatment, and genetic characteristics, as well as patients' knowledge about their own particular cases. We expected that patients whose spouses or parents were also diabetic would have a better understanding of their own conditions, and that patients with more education would have higher understanding. We also wanted to see whether the patients' age, duration of illness, and treatment methods would influence their understanding.

Previous studies have emphasized the family medical history in completely different ways. Many were concerned with developing and testing methods for extracting accurate information from the patient.^{1-3,5,7,8} Because these investigations focused on the act of taking a history or on the docu-

ment produced, they did not examine what the reported information meant to the patient himself. In a study designed to assess the accuracy of the family history method in affective disorders, Mendelwicz et al. reported that children and spouses of patients gave better reports about the patient's illness than did other members of their families.⁶ Although his study did not deal with diabetes, this result led us to hypothesize that a diabetic subject would likewise know more about the illnesses of his/her parents or spouse. Elinson and Trussell, in a study of factors related to the reporting of diagnostic information, concluded that interview reports of high school graduates were less likely to be adequate than the reports of people who had never attended high school, a conclusion that we challenged in our hypothesis.⁹ Elinson and Trussell also found that the adequacy of reports did not vary significantly for different age groups; we challenged this result as well. Our search of the literature did not reveal any studies that dealt with the family medical history and diabetes, or any studies that tried to determine the influence of the patient's duration of illness or treatment method on his/her understanding of disease. We did find several studies concerned with the feasibility and accuracy of switching from the interview method of obtaining histories, including questions about the family history, to the written questionnaire—a topic we will not address in this discussion.^{1,2,4,7}

METHODS

Patient population. We interviewed 51 low-income patients with adult-onset (type II) diabetes mellitus in the outpatient medicine clinic of a general hospital. There were 45 women and 5 men, with a mean age of 58.5 ± 10.5 yr. The mean duration of illness was 9.3 ± 7.2 yr, and 24 of the 50 patients had attended grade school, while the other 26 had attended high school.

Data collection. One interviewer (R.S.D.) conducted a single session with each patient and obtained the following: general information including age, education, and duration of diabetes; patients' descriptions of their diabetes and any other serious illnesses; patients' reports of any serious illnesses of grandparents, parents, spouse(s), mothers' siblings, fathers' siblings, and patients' own siblings. All patients were asked if they had a close friend with diabetes. **Determination of exposure**—if there was a positive family history (diabetes occurring in one or more members of the patients' extended families), the patients then described their extent of contact with each affected relative. If the patient saw his/her diabetic relative from daily to several times a month, or helped in that person's treatment (drive to the clinic, administered insulin, cooked meals, etc.) or talked to him/her specifically about diabetes and its treatment, the interviewer noted "extensive exposure." If the patient saw his/her diabetic relative less than monthly and did not talk about the disease, or if that relative lived in another town, the interviewer noted "limited exposure." This determination of exposure, although subjective, was made before the understanding questions (see below) were asked, and therefore should not have altered the results. **Understanding questions**—the interviewer asked two types of questions (total of 12 questions). The first type included general questions about the course, treatment, and genetic characteristics of diabetes, such as, Can having diabetes cause you to get any other conditions or diseases that you know of? The second type consisted of specific questions about the patient's own condition and treatment regimen, such as, What is your doctor doing to treat your diabetes? Each question was scored right or wrong according to predetermined criteria, and the number of correct answers constituted each patient's understanding score.

Data analysis. We analyzed the scores of 46 patients because 4 patients with negative family histories reported a close friend with diabetes. We dropped these patients from the analysis because we did not wish to delve into the nature of the friendship and felt that it could be a confounding variable.

RESULTS

The mean understanding score for the 46 diabetic subjects was 9.2 ± 2.3 . Twenty-two of the patients scored low (0–9), and 24 scored high (10–12) on the interview questions designed to assess their general knowledge about diabetes and their knowledge of their own particular conditions. Criteria for low and high scores were determined arbitrarily before the interviews.

TABLE 1
Understanding score based on family history

Family history	N = 46	Mean \pm SD
Positive	34	9.4 ± 2.4
Negative	12	$8.8 \pm 5.9^*$

* Not significant.

The data in Table 1 indicate that, overall, patients with a positive family medical history for diabetes did not have significantly better understanding than patients with a negative family history. However, if patients had a lot of exposure to their affected relatives (Table 2), or if those relatives included a spouse or a parent, as opposed to a sibling or other relative (Table 3), the mean understanding was significantly improved ($P < 0.05$). The separate contributions of having a diabetic parent versus a diabetic spouse were not obtained, since only 2 patients who had a spouse with diabetes did not have a parent with the disease as well. Similarly, patients with diabetic siblings were analyzed together with patients who had some other diabetic relative, since only 3 of the 12 patients in this group reported a diabetic relative who was not a sibling.

To test for a possible association between exposure and family relationship, we did a chi-square analysis using patients who had a diabetic spouse and/or parent with high exposure, and with patients with other diabetic relatives with low exposure; we found that our results in Table 3 were not due to exposure alone.

The scores of patients who attended high school ($N = 24$) were not significantly different from the scores of patients who had attended only grade school ($N = 22$). For the first group, the mean score was 9.6 ± 2.5 , and for the latter group it was 8.9 ± 2.5 .

Of the 46 patients, we found that 4 were treated with diet alone, 11 received oral hypoglycemics in addition to their diabetic diet, and 31 were maintained on diet and insulin. The diet-alone group was too small to analyze, and we found no significant difference in understanding between the patients in the other two treatment groups.

The correlation between age and understanding was not statistically significant, although patients' scores tended to decrease with advancing age. Similarly, duration of diabetes did not correlate significantly with understanding. We want to note, however, that understanding was highest for patients recently diagnosed (≤ 1 yr, $N = 5$), and dropped

TABLE 2
Understanding score based on degree of exposure

Degree of exposure	N = 34	Mean \pm SD
Extensive	21	10.1 ± 1.7
Limited	13	$8.1 \pm 2.9^*$

* $P < 0.05$.

TABLE 3
Understanding score based on familial relationship

	Low score (0-9)	High score (10-12)
+ Family history (spouse and/or parent)	7	15
+ Family history (sibling and/or other relative)	8	4*

* $P < 0.05$.

sharply in the group of patients who had had the disease for 2-5 yr ($N = 13$).

DISCUSSION

The family medical history can provide models for educating patients about disease, especially a disease such as diabetes that tends to run in families. However, despite this educational potential, we found that if no other variables were taken into account, patients with a positive family history for diabetes did not have significantly better understanding of their own disease than similar diabetic patients with a negative family history. We believe that this result does not indicate a lack of perception on the part of patients, but rather, a need on the part of physicians to expand their notions of what constitutes a positive family medical history, and of how it can be used in educating patients.

Some of the other results we obtained in this preliminary investigation may be helpful in the task of defining a positive family history. For example, we found that patients who had a diabetic spouse or parent also had significantly higher understanding than patients with a diabetic sibling or other relative; patients with a lot of exposure to an affected relative had better understanding than patients with limited exposure. We, therefore, believe that taking a family history must involve special focus on the relationship of the patient to any ill relative he/she has named as well as a careful determination of his/her degree of exposure to that relative. Of course, the variables of exposure and relationship are not mutually exclusive, since we tend to see more of our closer relatives. Nonetheless, our analysis showed that relationship and exposure contributed independently to understanding. Thus, until we know the specific contribution to understanding made by the two variables, we must continue to look at these factors separately; any educational interventions we design must take them both into account.

Our finding that, overall, level of education made no significant difference to understanding invites much speculation. We found that most of the patients in our study knew which medications they took for their diabetes, and could name the type and dosage of insulin; this, then, is an important area in which patient education has been effective. On the other hand, few patients were aware that stages of diabetic retinopathy are detectable on funduscopic exam. Although most knew that blindness is a possible complication of diabetes, they expected it to happen suddenly, without prior warning. The patients identified many sources for their information in the course of the interviews. Several mentioned

that they had gotten books from the library or had seen newspaper articles or television commercials about diabetes. A few patients said that their doctors had explained things, while even more referenced some "old wives' tale," or a fellow patient. These sources of information are equally accessible to patients with all levels of education, a fact that we find hopeful; probably no patients need be "spared" a detailed explanation of their disease because they are illiterate or unfamiliar with disease concepts. Since treatment method and age did not significantly contribute to understanding, we can probably say that a difficult regimen or relatively advanced age will not necessarily make it difficult for a patient to understand his/her condition either. Our finding that understanding dropped sharply after patients had had diabetes for over a year supports our belief that the timing of educational interventions is also critical. Patients most need information after they have gotten used to their diagnosis and the subsequent changes in their life-styles, but before the onset of complications and more severe symptoms, i.e., in their second and third year of diabetes.

Pertinent to our discussion is the work of Kleinman et al., including his concept of a disease/illness dichotomy that exists in modern medical practice. Illnesses are the culturally influenced, subjective experiences of being sick for which most people seek medical attention; diseases, on the other hand, are the definable entities that we in "biomedicine" spend our time diagnosing and treating.¹⁰ We found many examples of this dichotomy, especially when questioning patients about the pathogenesis of diabetes. When asked, How does someone come to have diabetes, or what goes wrong in your body when you have it? a few patients thought that it was contagious while most suspected that it came from eating too much sugar/starch when they were young. Kleinman et al.'s socio-anthropologic approach provides us with another way of stating what we hope is a new function for the family medical history in patient care. The way the physician uses it, the family history belongs to the realm of disease; it is made up of the labels that various family members have collected and eventually died from over the years. To the patient, the family history is less defined, and situated in the realm of illness; it consists of various individuals and their idiosyncrasies of appearance and life-style that manifest episodes of being ill. Thus, the family medical history can function as a two-way explanatory model through which the physician gains information from and about his patient while he educates according to the medical model of disease at the same time. To cultivate this function, we must do more studies to discover, define, and expand our notions of the family medical history.

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